



**Increasing Opportunities in Biobehavioral Research:
Working Group Utilizing Allergic Bronchopulmonary
Aspergillosis (ABPA) as a Framework**

**National Institute of Nursing Research
and
Office of Rare Diseases**

National Institutes of Health

**Four Points Sheraton Hotel
Bethesda, MD
July 15-16, 2004**

Agenda

July 15, 2004

7:30 - 8:00 Registration

8:00 - 8:10 Opening Remarks

Dr. Patricia A. Grady

8:10 - 8:20 Introduction of Participants

Dr. Karen Huss

8:20 - 8:30 Overview & Purpose of
Conference Working Group

*Dr. Karen Huss
Dr. Pamela Mitchell*

Conference on Increasing Opportunities in Biobehavioral Research

Workshop Objectives: This session covers critical issues and the challenges of Biobehavioral Research.

- 8:30- 9:00 Utilizing Rare Diseases as Models for Biobehavioral Research**
Dr. Paul Greenberger
Dr. Janet Larson
- 9:00 - 9:20 Current State of Biobehavioral Research in Symptom Management in Diseases Characterized by Immune & Inflammatory Responses**
Dr. Duck Hee Kang
- 9:20- 9:45 Methodology**
Dr. Barbara Waag Carlson
Dr. Susan Jansen
- 9:45 - 10:15 Response & Discussion**
Dr. Susan Janson
Dr Carolyn Yucha
- Gaps and Research Challenges
 - Potential Research
 - Research Training Opportunities
 - Research Needs
 - Disseminating Meeting Results
- 10:15- 10:30 Break**
- 10:30 - 11:15 Designing Multidisciplinary Biobehavioral Research** *Dr. Pamela Mitchell*
Dr. Nelson Lim
- NINR Funded Biobehavioral Research
 - Cross Fertilization of Nurse Researchers from other Fields into Rare Diseases such as ABPA Research
 - Existing Strategies
 - Barriers to Execution
- 11:15- 11: 45 Responses & Discussion** *Dr. Janet Brody*
- Key Research Areas of Study
 - Design and Barriers
- 11:45 - 12:45 Working Lunch**

- 12:45- 1:00* Recap of Morning Session *Dr. Pamela Mitchell*
- 1:00 - 1:30* Identification of Current Biobehavioral Measures *Dr. Monica Jarrett*
- Immune Responses
 - Symptom Management
 - Adherence to Treatment Regimen
- 1:30- 2:00* Theoretical Framework: Factors of Environment, Family, and Individual with Cellular Multilevel Methods and Analysis *Dr. Susan Czajkowski*
- 2:00 - 2:30* Responses & Discussion *Dr. Alice Kornblith*
- 2:30 - 3:00* Identification and Evaluation of Existing Biobehavioral Measurement Techniques Appropriate for Conducting Clinical Research Among Patient Populations using ABPA as a Model *Dr. Paula Meek*
- 3:00 - 3:30* Response & Discussion *Dr. Robert Hamilton*
Dr Daniel Powers
- 3:30- 3:45* Break
- 3:45 - 4:15* Biobehavioral Tools Appropriate for Conducting Research with Vulnerable Populations, such as Children and the Elderly using the ABPA Model *Dr. Jackie Dunbar Jacob*
- 4:15 - 4:45* Response & Discussion *Dr. Karen Huss*
Dr. Pamela Mitchell
- 4:45 - 5:15* Gaps in Biobehavioral Knowledge *Dr. Margaret Heitkemper*
- Skills/Knowledge Needed by New Investigators Entering Biobehavioral Research
 - Skills/Knowledge Needed by Experienced Researchers Transitioning to Biobehavioral Research
- 5:15 - 5:30* Response & Discussion (To include synopsis of day and logistics for tomorrow) *Dr. Karen Huss*
Dr. Pamela Mitchell

July 16, 2004

Challenges in Biobehavioral Research Design and Measurement
Cont'd.

8:00 - 8:45 Chairperson's Recap of Day One

Dr. Karen Huss
Dr. Pamela Mitchell

8:45 - 9:30 Core Knowledge in Biobehavioral Research

Dr. Mary Kerr

- Prioritize Key Recommendations From Yesterday's Sessions
- Factors Associated With Development and Evaluation of Biobehavioral Interventions
- Integration of the NIH Roadmap

9:30 - 9:45 Responses & Discussion

Working Group

9:45 - 10:15 A Model Program in Behavioral Social Science Research

Dr. Stephane Philogene

- Identify collaborative research opportunities with NINR
- Practicum Options

10:15 - 11:15 Responses & Discussion

Working Group

11:15 - 11:30 Break

11:30 - 12:30 Future Opportunities in Biobehavioral Research

- Participant Recommendations *Working Group*

12:30 – 1:30 Working Lunch

Reaching Consensus on Research Gaps and Addressing These Gaps

1:30 - 2:00 Next Steps, Wrap-up & Adjourn

Working Group

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National Institutes of Health
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Purpose:

The overall objectives are to bring together a group of biological, behavioral, and immunological experts to examine existing body of knowledge and develop recommendations on methods and approaches for future research. The expert working group will discuss the need for training in biobehavioral research related to rare diseases. Allergic bronchopulmonary aspergillosis (ABPA) will be the model condition used to identify future research opportunities in biobehavioral research.

Goals:

Specific goals include:

1. Identification of existing biobehavioral measures which are relevant to research in ABPA.
2. Evaluation of existing biobehavioral measurement techniques appropriate for conducting clinical research among patient populations with ABPA.
3. Identification of biobehavioral tools appropriate for conducting research with vulnerable populations, such as children and the elderly.
4. Identification of gaps in biobehavioral knowledge that can be addressed by the research agenda of the NINR and ORD.

Background: This rare disease was selected to represent a condition that has significant implications for symptom management, a major focus at NINR. ABPA was used as an exploratory model to illustrate the challenges in biobehavioral research. Discussions focused on recommendations for researchers for biobehavioral methods of measurement and analysis using interdisciplinary/biobehavioral approaches. There are many barriers to research in rare diseases. Some of these are related to the nature of diseases with small patient populations and some are broaden concerns associated with carrying out biobehavioral research with patients along the natural history of an illness. Presenters discussed these barriers and identified gaps and approaches for future research.

Format: Solicited paper presentations on agenda topics, Responses, Discussion, and Future Recommendations